

Advancing health literacy: Building bridges

Sept. 16, 2008

National Institute for Literacy Webcast

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Health is a resource for life, not the object of living.

- Ottawa Charter for Health Promotion

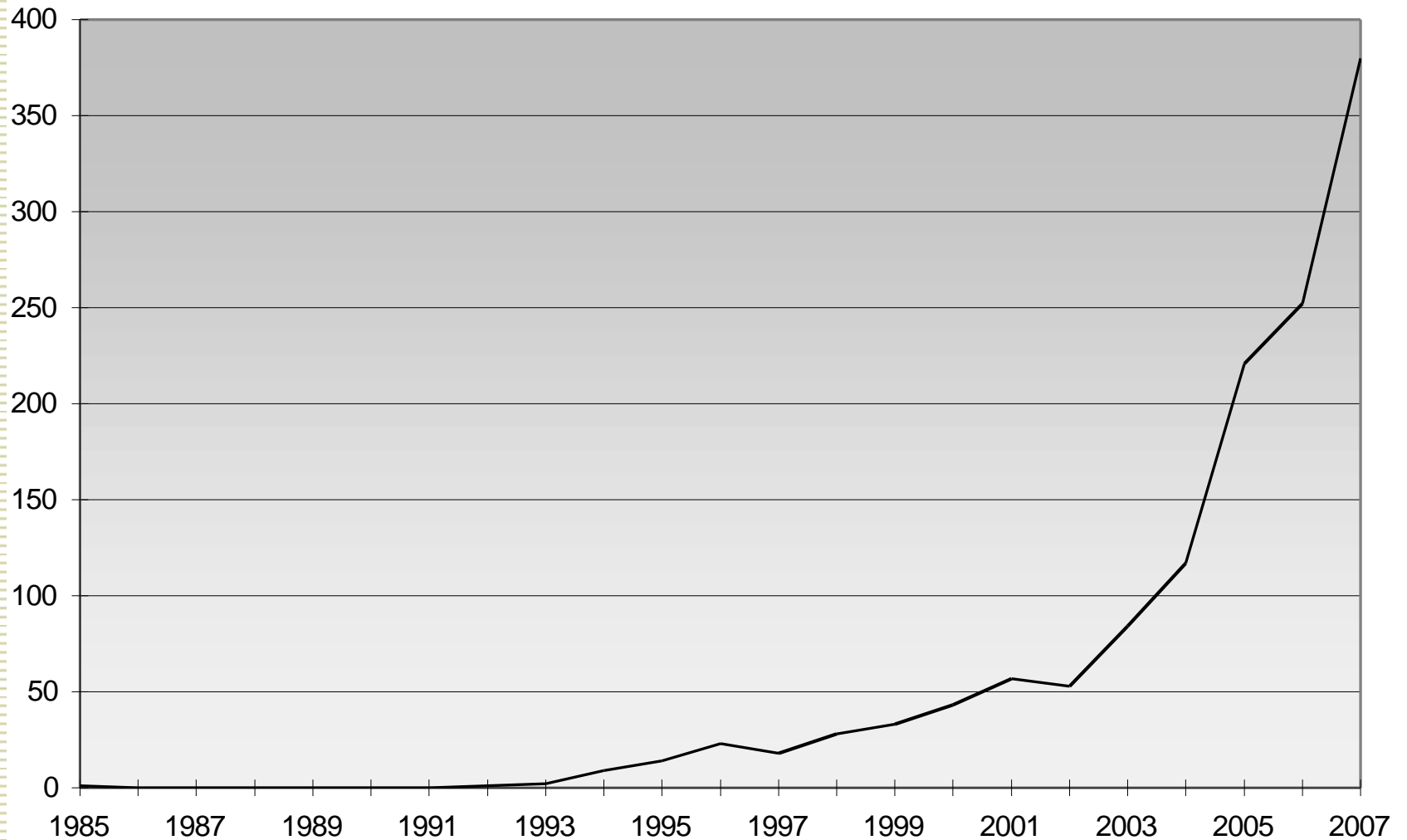
A little background ...

- ◆ Two original streams of research and practice – with multiple definitions of health and literacy.
 - **health care professionals** - investigating relationships between literacy and health, attempting to improve health information materials and physician/nurse communication skills.
 - **adult basic education/ literacy professionals** - incorporating health into curricula and community empowerment efforts.



Health literacy peer-reviewed journal articles by year

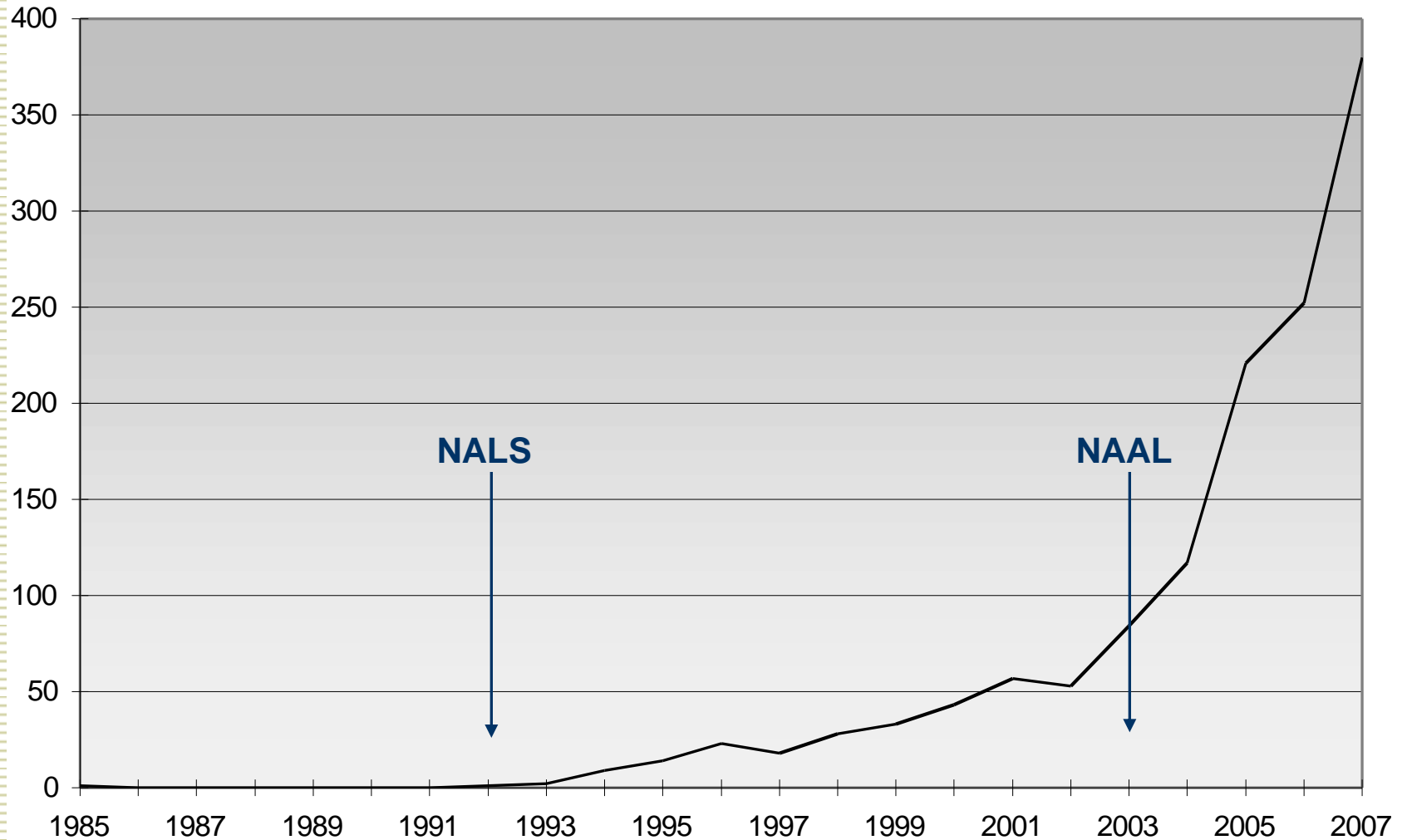
Total = 1,336



Databases: PUBMED, ISI Web of Science, Academic Search Premier, CINAHL, ECO, Ingenta, Science Direct

Health literacy peer-reviewed journal articles by year

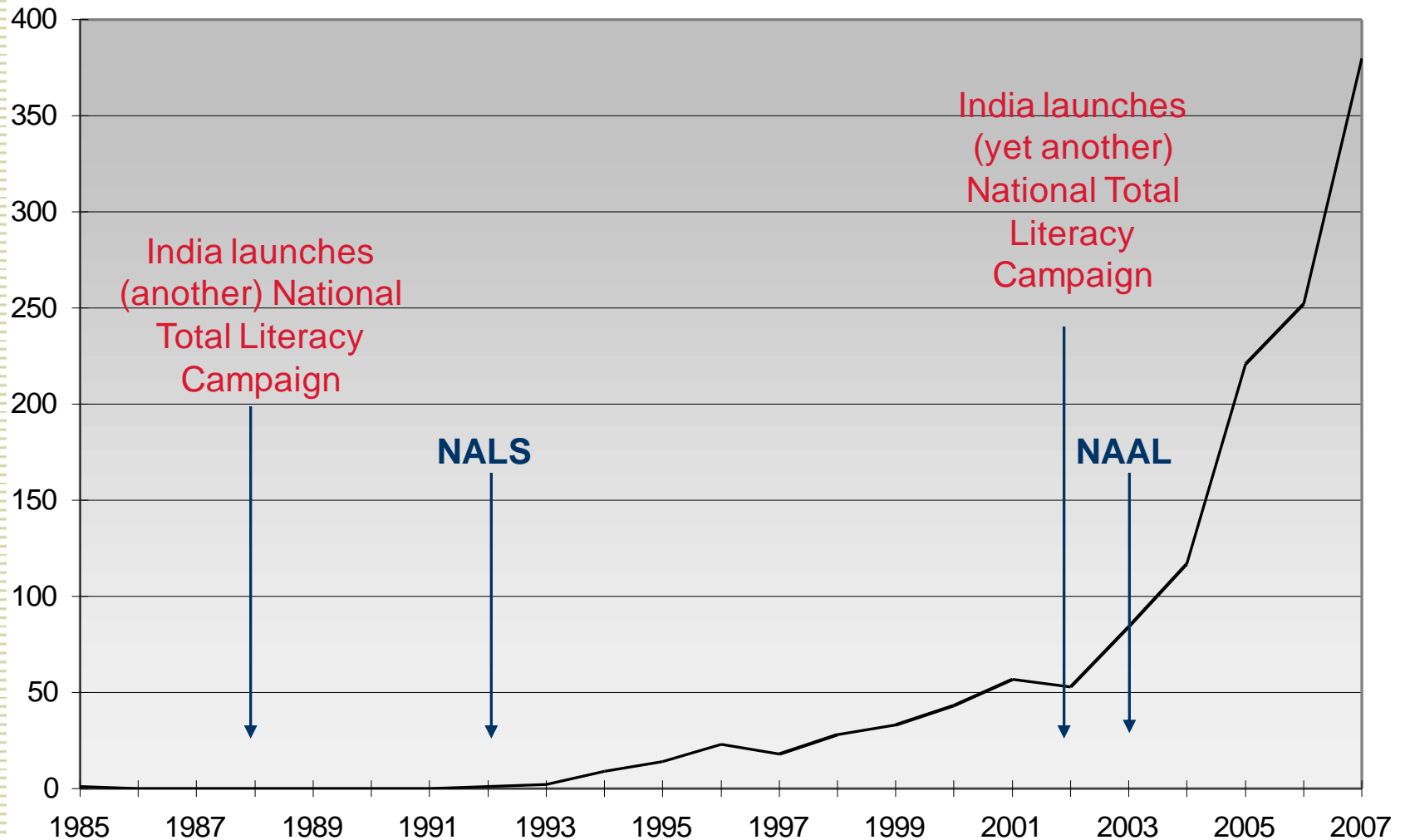
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Health literacy peer-reviewed journal articles by year

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Why all this interest here & now?



Changing conditions ...



- ◆ A changing global burden of disease:
 - **from** communicable diseases and acute conditions
 - **to** lifestyle-related and chronic conditions.
- ◆ Since the beginning of the 20th century, most major advances in health are due to the application of new knowledge and technologies (World Bank, 2002).

Increasing inequities

- ◆ From 1960-2002 - **IF** everyone in the U.S. experienced the same health gains as whites in the highest income group,
- ◆ 14% of the premature deaths among whites and
- ◆ 30% of the premature deaths among other racial & ethnic groups
- ◆ **would have been prevented.**

(Krieger et al., 2008)



Increasing inequities



Almost 5,000,000 people.

(Krieger et al., 2008)

Navigation barriers

- ◆ At a large urban teaching hospital in New Jersey ...
- ◆ In 73% (7 of 10) of health literacy based tasks, students could not find a destination without help from staff.
- ◆ In nearly half (45%) of tasks, students needed to ask for help from more than one staff member.
- ◆ “Looking lost” - 75% of attempts walked around the same nursing station looking lost 6 times w/out help. Nurses worked to not ‘see’ them.

More – and more complex – interfaces

- ◆ **Health information** = multiplication of sources
- ◆ **Health insurance** = complex bureaucracy
 - Part D - over 40 plans in some states
- ◆ **Chronic disease prevention** = lifestyle changes
- ◆ **Chronic disease treatment** = self-management often involving technology
- ◆ **Acute issues** = doc/ patient communication
- ◆ **Medical mistakes** = checklists; navigation


The U.S. pays more per person and gets less in health than any other industrialized nation

An issue that is not going away soon

- ◆ Graduation rates for the principal school districts in the 50 largest U.S. cities (2003-4)

- ◆ **51.8%**

- EPE Research Center, 2008 Available:
<http://www.americaspromise.org/APA.aspx>



Nearly half of us
have been
left behind.



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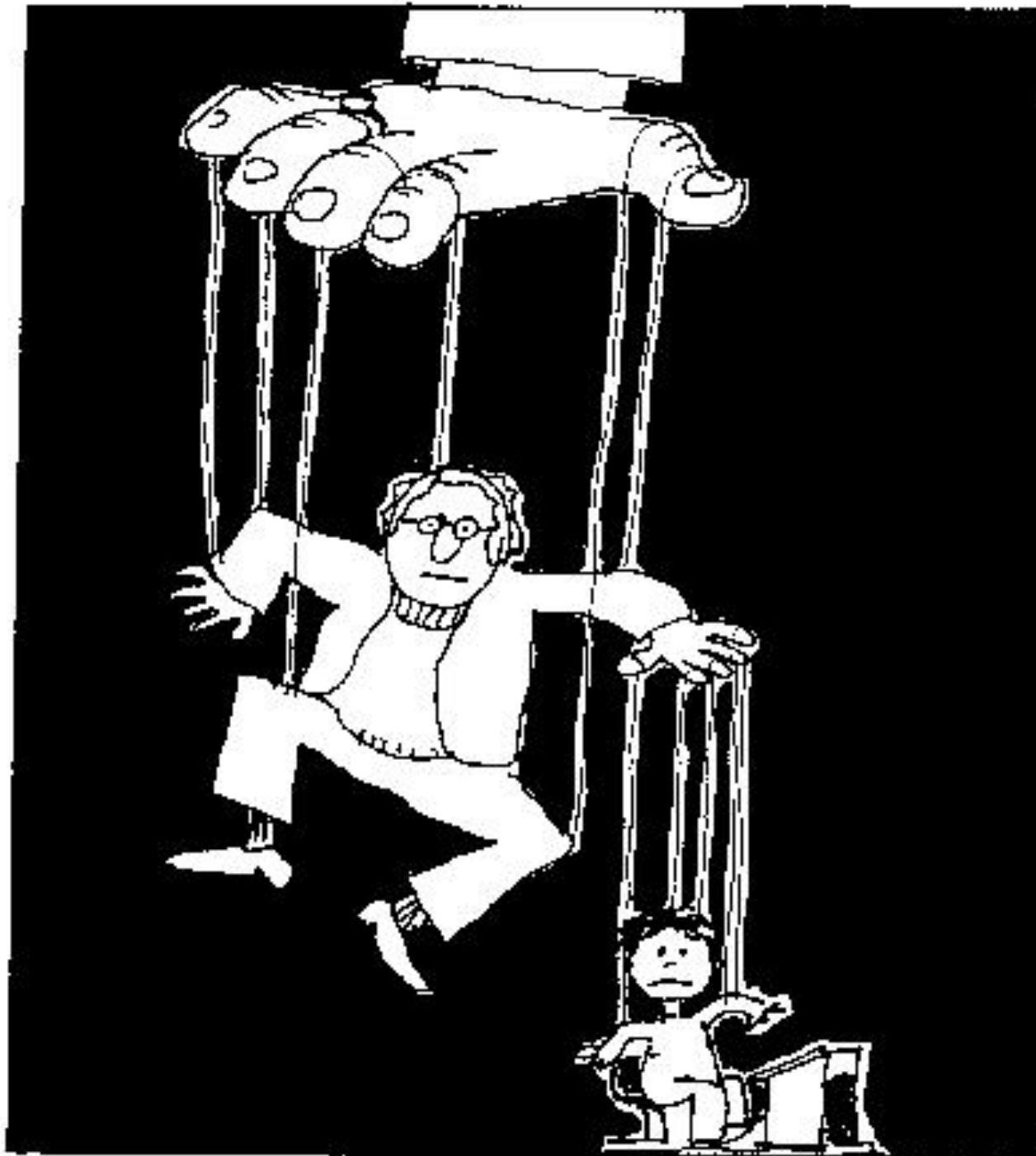
- EPE Research Center, 2008 Available:
<http://www.americaspromise.org/APA.aspx>



Health literacy today



- ◆ Has come a long way in a short time!
- ◆ But ... Risks being co-opted into only providing “plain language” materials.



- A good document mired in a bad system is still ineffective (if it is used at all) and could even be harmful.

We must expand the discourse about health literacy

- ◆ **From ... a primary focus on fundamental literacy in health.**



- ◆ **To ... a complex social determinant of health and an empowerment model.**
- ◆ **Address the symptoms and the causes.**

Some of the differences

(Pleasant & Kuruvilla, 2008)

Fundamental literacy in health model

- ◆ Simple screening tools
- ◆ Individual focus
- ◆ Rewriting as a primary practice
- ◆ Often focus on clinical encounters
- ◆ Often blames individuals as lacking
- ◆ Source of most empirical data

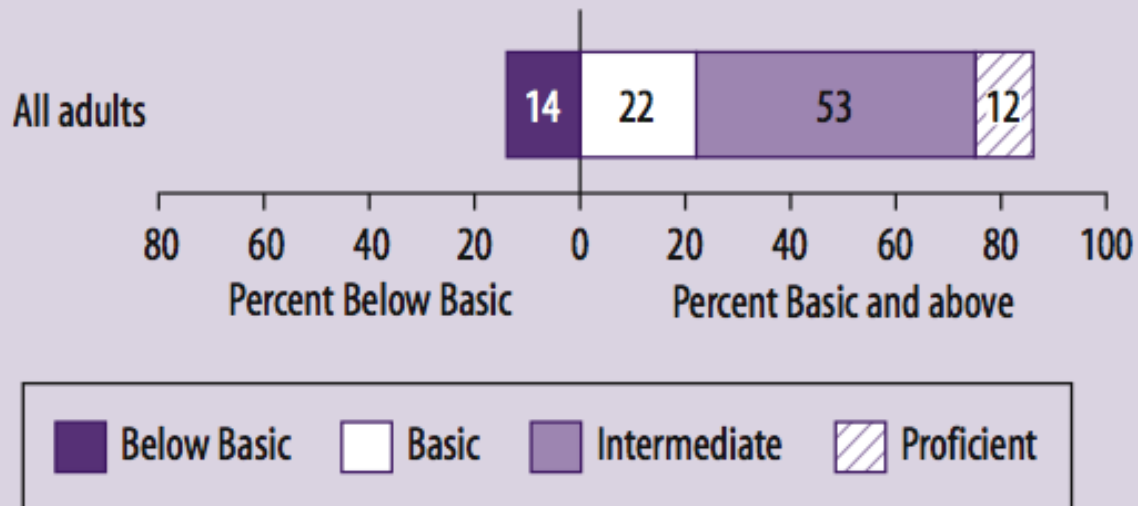
Social determinant/empowerment model

- ◆ No current measure
- ◆ Population focus
- ◆ Seeks system change
- ◆ Seeks to identify social-political causes
- ◆ Health literacy is a problem for all
- ◆ Source of most theories/conceptual frameworks

Just one brief example: Changing the discourse

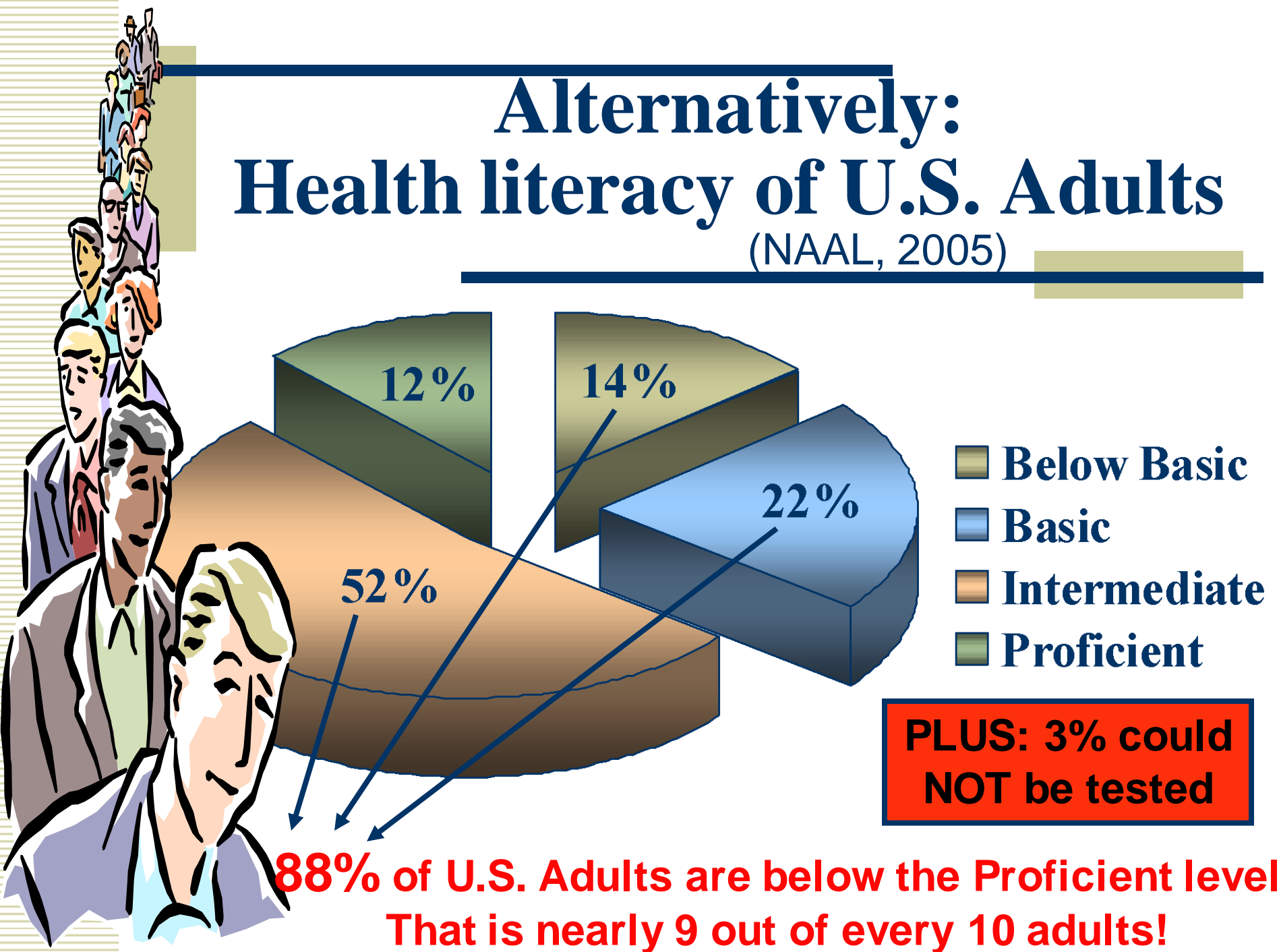
Where is the ‘problem’ with health literacy?

Figure 2-1. Percentage of adults in each health literacy level: 2003



Alternatively: Health literacy of U.S. Adults

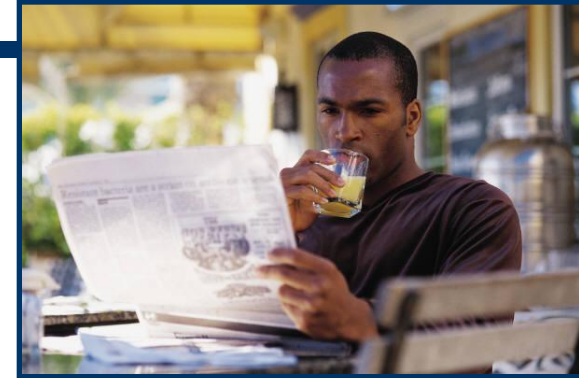
(NAAL, 2005)



(By the way) Proficient means ...

12% of participants could generally:

- ◆ Find the information needed to define a medical term in a complex document.
- ◆ Judge information to decide which legal document applies to a specific health care situation.
- ◆ Calculate an employee's share of health insurance costs for a year using a table based on income and family size.



income

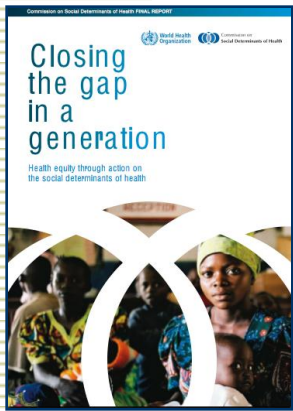


Family size

A Mismatch ...

- ◆ 88% (88 of 100) of the country is below the proficient level in health literacy.
- ◆ Over 300 studies have demonstrated that most health materials are beyond the comprehension skills of most Americans.



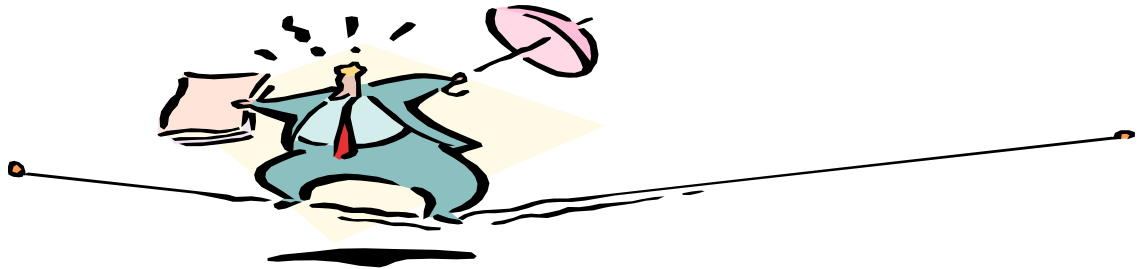


Hot off the press

- ◆ World Health Organization Commission on Social Determinants of Health (Aug. 29, 2008). In the context of arguing, **“Social injustice is killing people on a grand scale.”**
- ◆ The authors state ...
- ◆ “The scope of health literacy should be expanded.”
- ◆ “Health literacy is not just about the individual’s ability but also the ability of public and private sector actors.”
- ◆ **“Improving health literacy is an important element of strategies to reduce health inequity.”**

Advancing health literacy will require multi-sector partnerships

- ◆ Generally, no single sector (or individual) has the range of resources required to launch comprehensive health literacy interventions.
- ◆ Therefore, bridging of the various sectors and perspectives on health literacy is needed.
- ◆ Focus on active engagement versus passive learning.



There is a golden rule

Know your audience

- ◆ ... the audience you have (or might)
- ◆ ... the audience you want



Golden rule #2



- ◆ Don't go it alone --
Involve your
audience early and
often!

Health literacy is complex

- ◆ The wide range of skills and competencies that people develop to **seek out, comprehend, evaluate, and use (communicate)** health information and concepts to make informed choices, reduce health risks, reduce inequities in health, and increase quality of life in a variety of settings across the life-course.

(Zarcadoolas, Pleasant & Greer, 2003; 2005)

(World Health Organization, 2008)

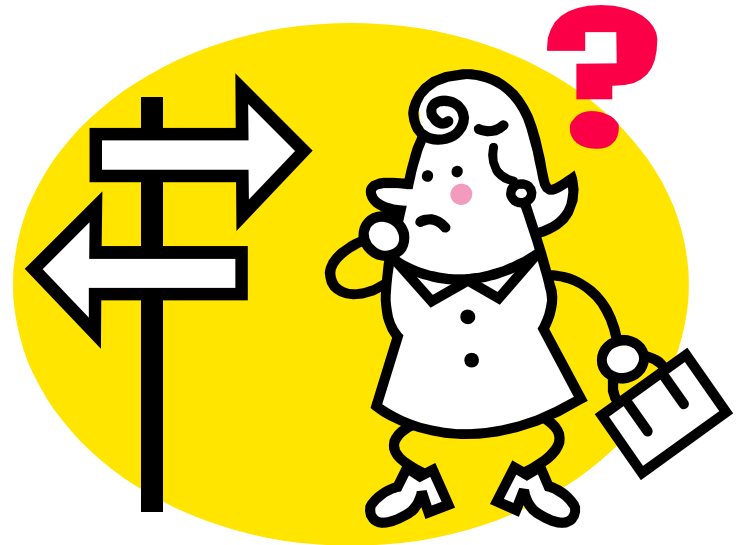
(Rootman & Gordon-El- Bihbety, 2008)

... and encounters complex challenges


- ◆ Think of your own health literacy experiences, you'll find barriers or bridges in these four areas:
 - **Fundamental** - reading, writing, speaking, numeracy
 - **Civic** - Understanding & navigating power relationships
 - **Scientific** - Complexity, change, technology; public health vs. clinical decisions.
 - **Culture** - NOT just race and ethnicity

The first (but not only) challenges to collaborating

- ◆ Lack of shared vocabulary
 - Patient safety?
 - Quality improvement?
 - Ambulatory care?
 - NAAL?
 - TABE?
 - ABE/ENL/ESL/ESOL?
- ◆ Capacity to deliver the ‘goods’
- ◆ Herding cats



Foot in the door strategies

- ◆ Learn a new language - be an adult learner
- ◆ Speak up in public
- ◆ Ask questions (more than 3) 
- ◆ Frontal assault via staff
- ◆ Frontal assault via board members
- ◆ Build a coalition – gain attention, aggregate power
- ◆ Find a funder
- ◆ Propose a solution versus identify a problem
- ◆ Outside expert/ National organization

The opportunities

- ◆ Shared goals are in place already!
 - Better health, equity, and health system performance.
- ◆ Uniquely complimentary resources
 - You must demonstrate that to people (including yourself)
- ◆ The health care system is steadily being told to do it
 - E.g. The Joint Commission; Health Literacy Act 2007
- ◆ Adult learners generally want to do it
- ◆ The long-term payoffs seem greater than the short-term costs
- ◆ It is the right thing to do.

The cautions

- ◆ Do not over promise - you don't have to.
- ◆ Evaluate – first, last, and always.
- ◆ Academic partners can help, but bring baggage.
- ◆ Publish or perish – share what you learn.
- ◆ Define a sustainability plan.
 - Learning capacity = ability to respond to change



Do NOT forget

- ◆ Departments of Public Health
- ◆ Area Health Education Centers
- ◆ Federally Qualified Health Centers
- ◆ Departments of Environmental Health
- ◆ K-12 school system
- ◆ Land Grant/ University Extension partners

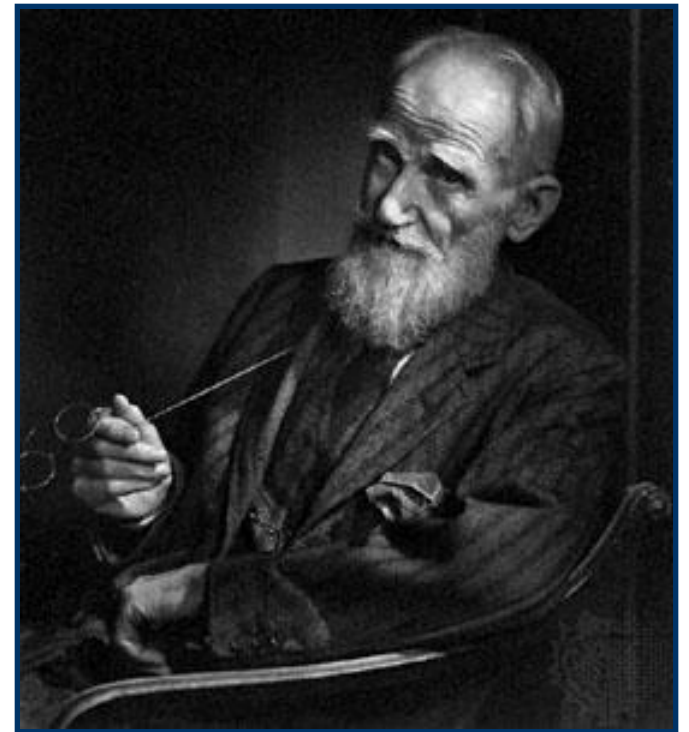
And remember ...

*The biggest problem
with communication
is the illusion that it
has occurred.*

-George Bernard Shaw

Don't believe that?

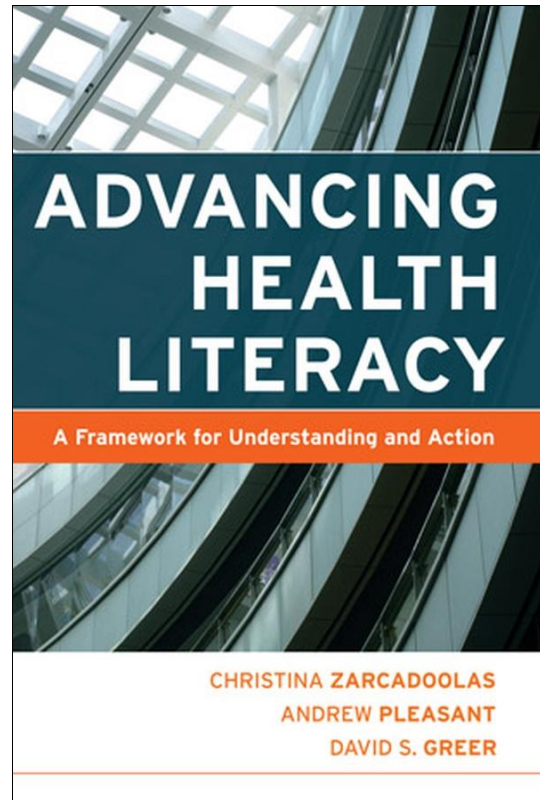
Think ... "Informed" consent



Please share your questions ...

Interested in
health literacy
curricula
development?

Come join the
discussion in
Calgary.



Available at
your favorite
online book
seller

Thank you.

Women's Health and Literacy

Ian M. Bennett MD PhD

Department of Family Medicine and Community
Health, and Graduate School of Education,
University of Pennsylvania

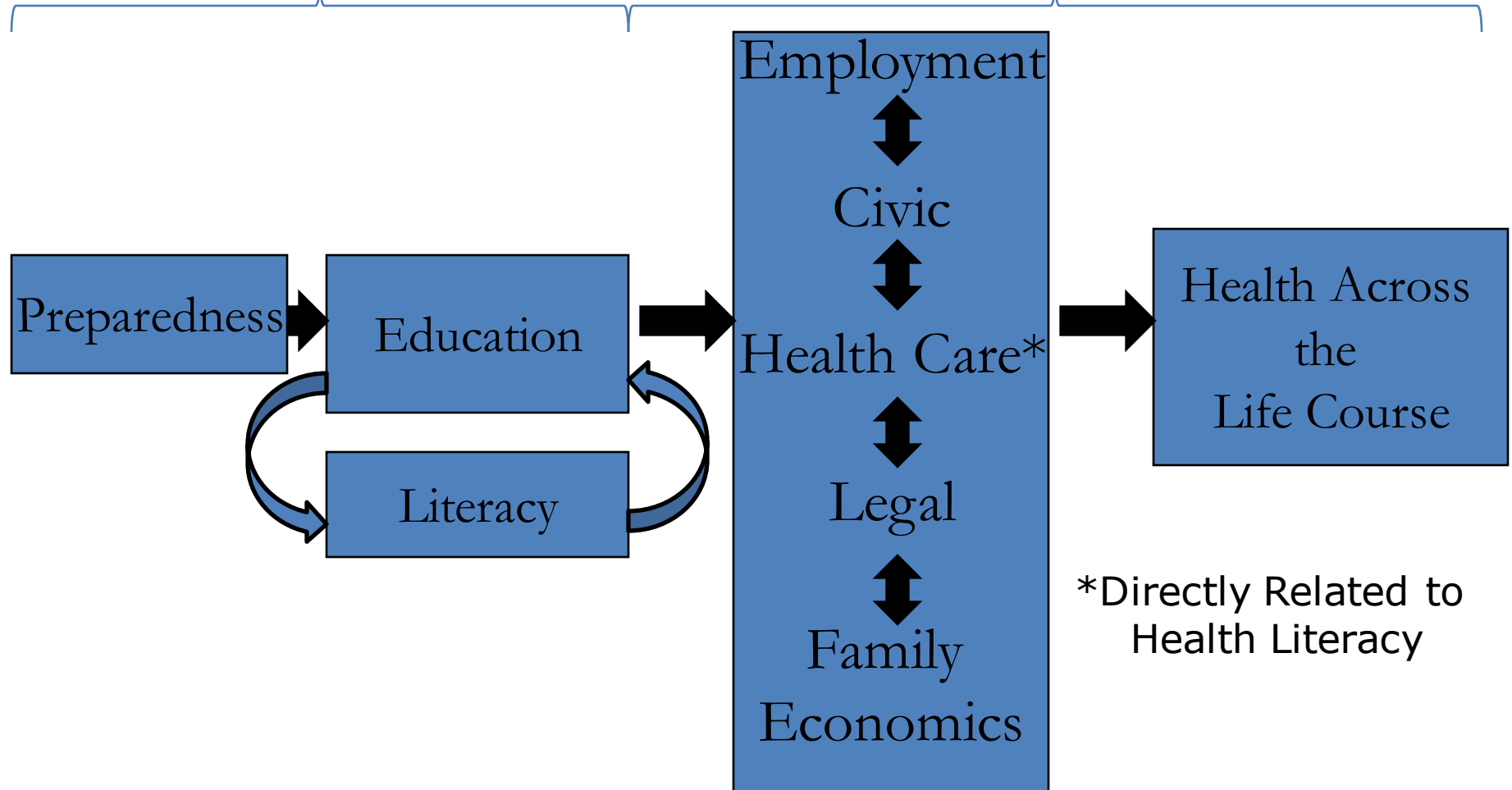
Philadelphia, PA

September, 2008

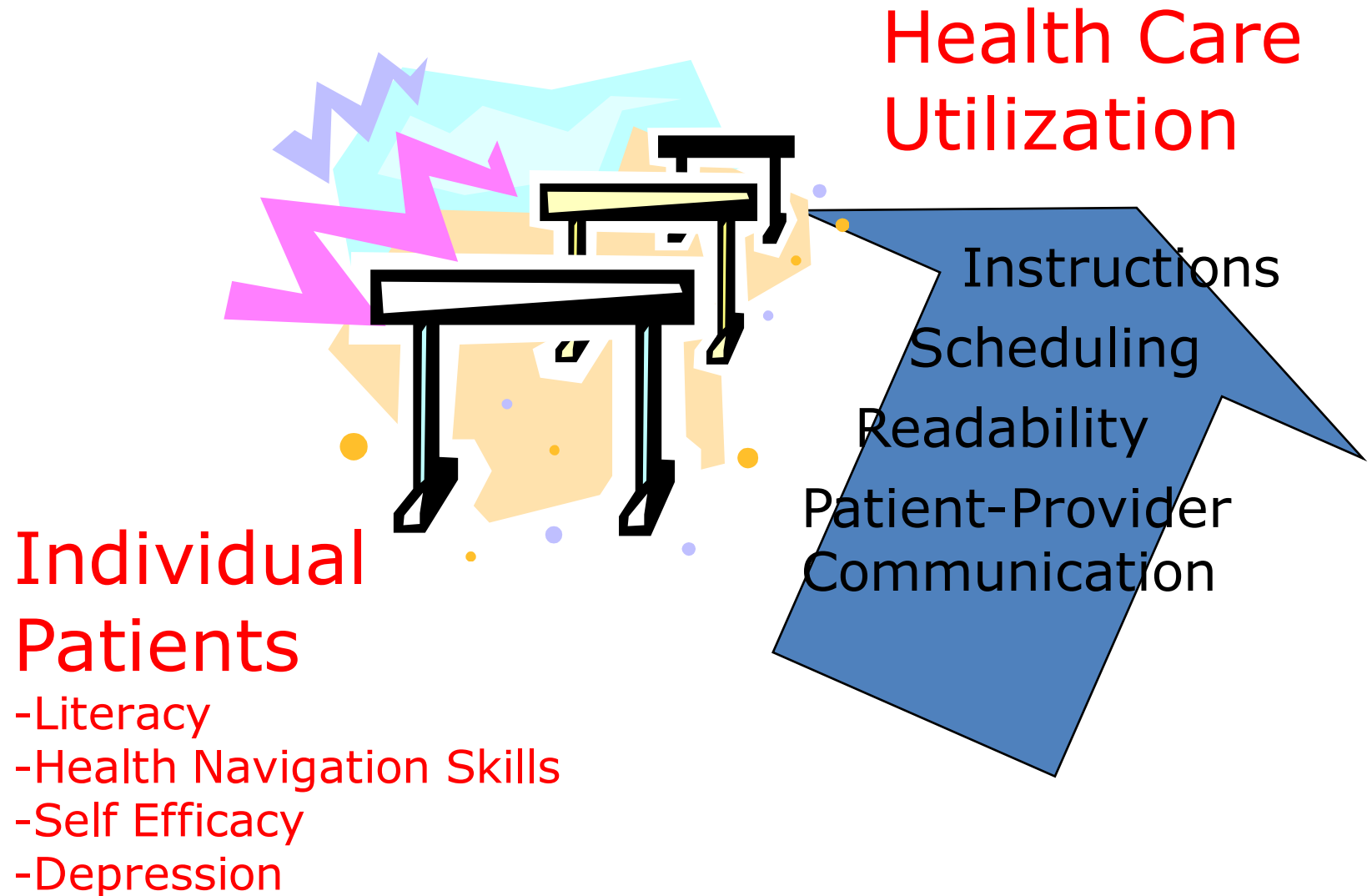
Literacy/Education and Health Through the Life Course

Child

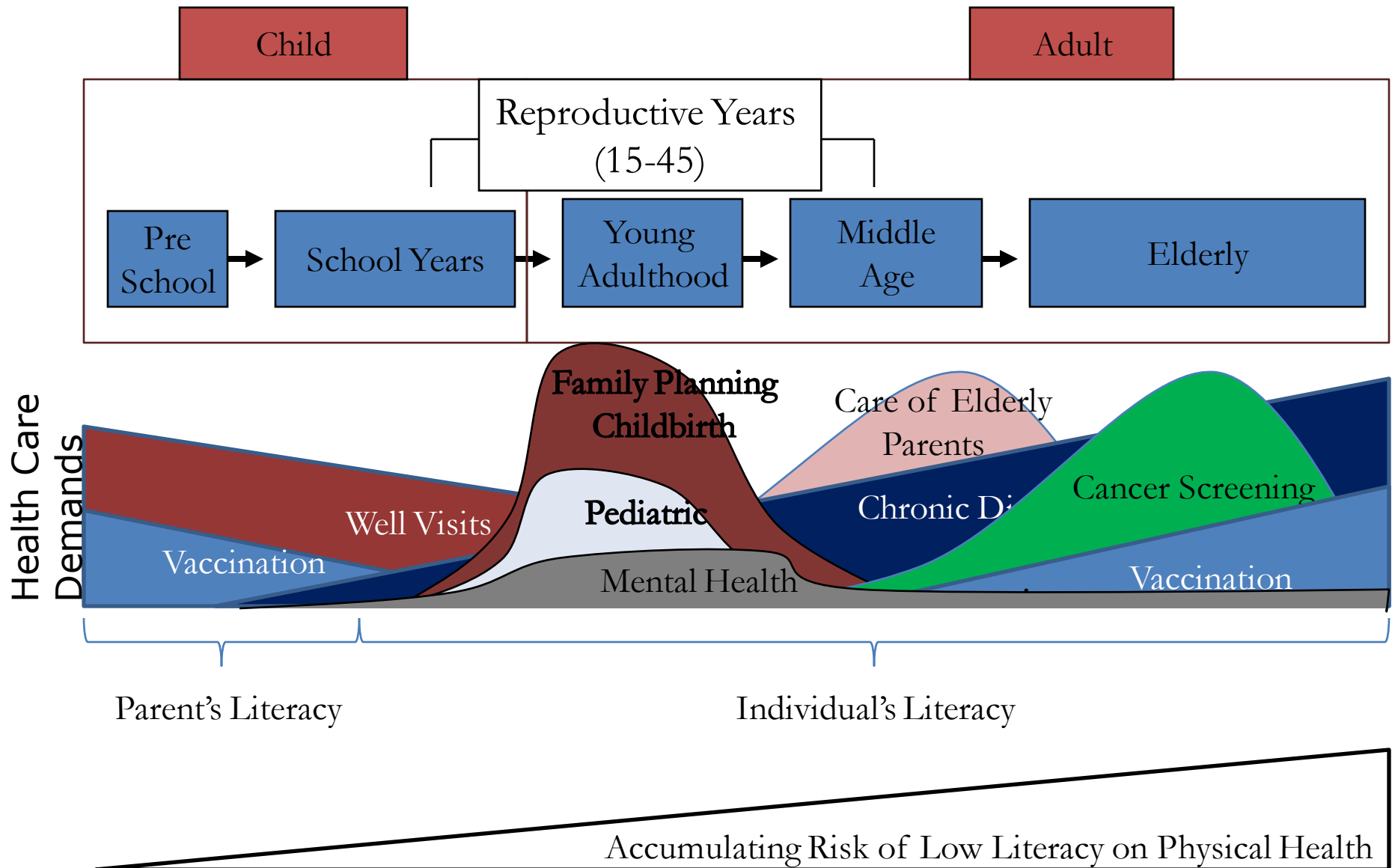
Adult



Hurdles to Health Care

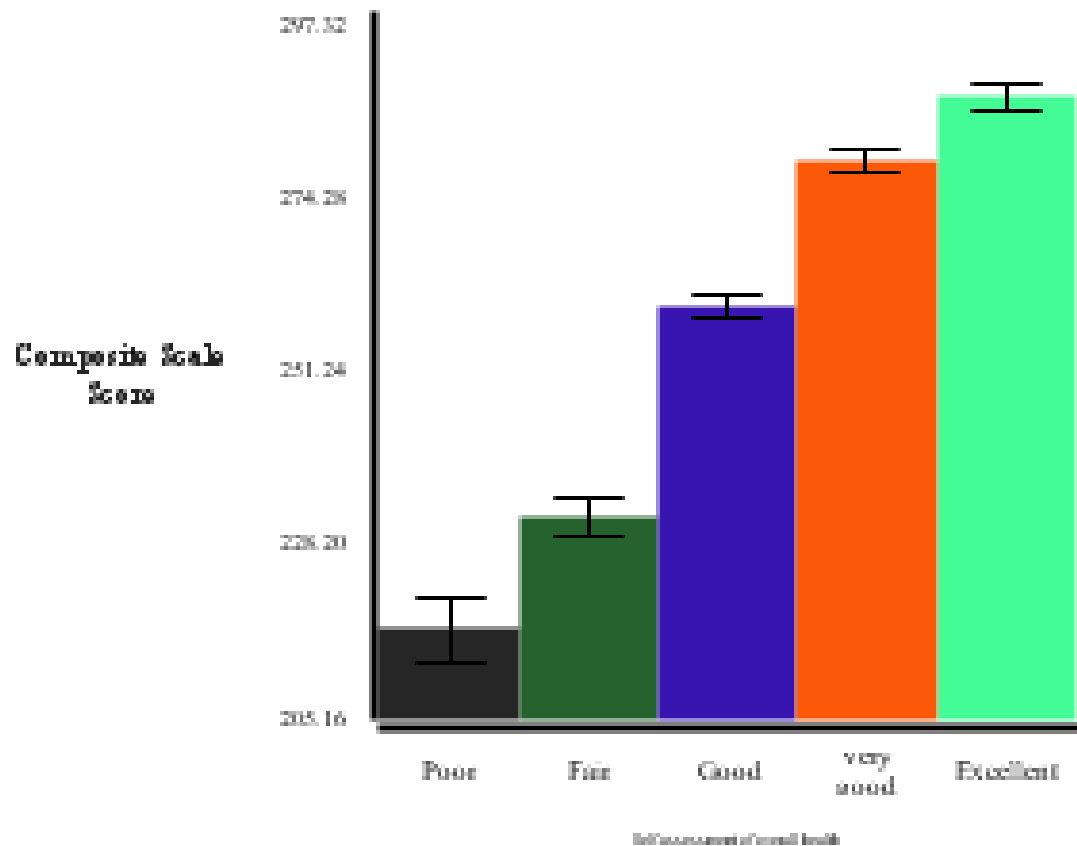


Health Literacy Needs Through the Life Course for Women



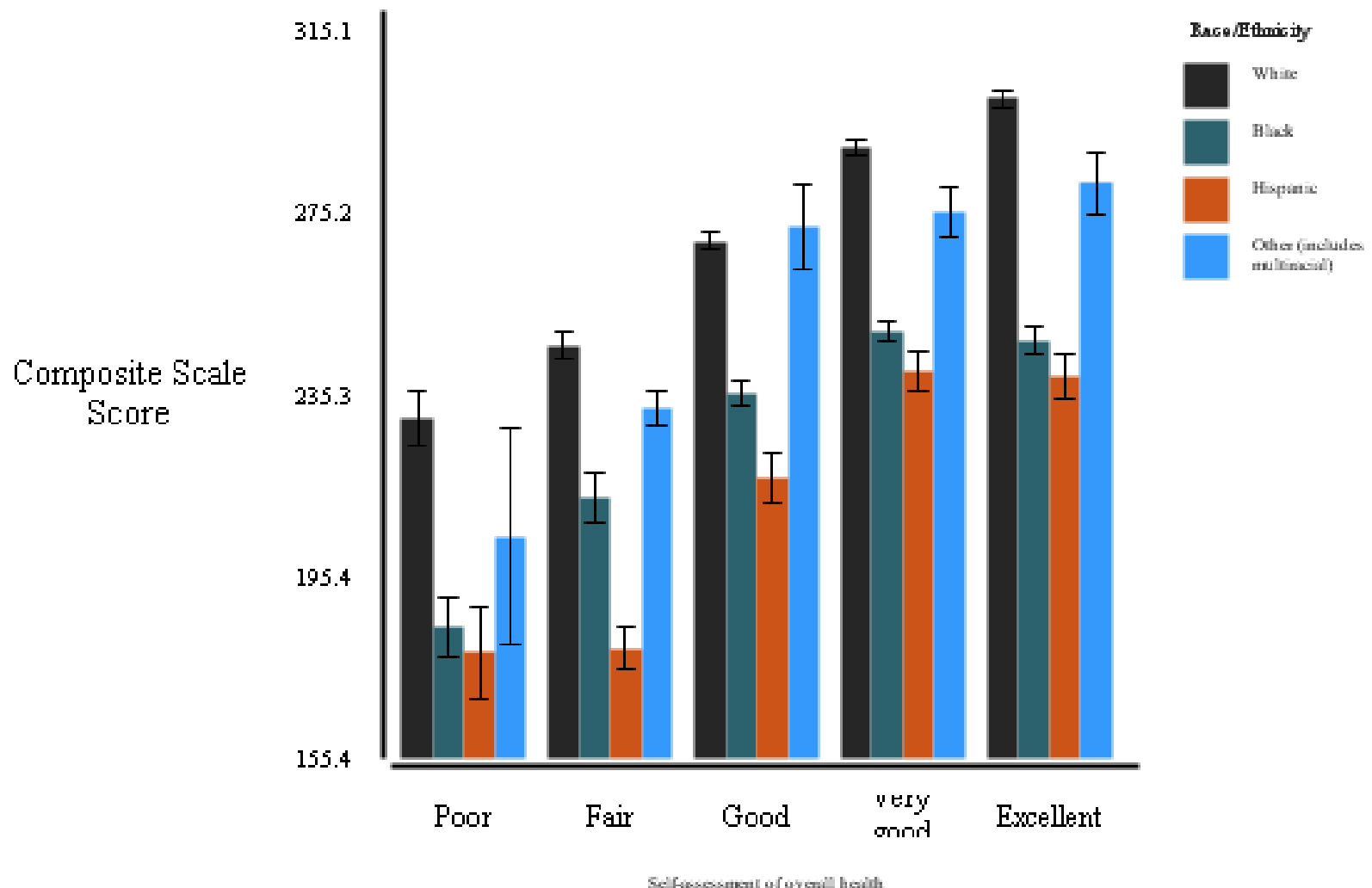
Self-Reported Health and Literacy Among Women Age 16-24 in the US

2003 National Assessment of Adult Literacy (NAAL)



Disparities in Self-Reported Health and Literacy Among Women Age 16-24

2003 National Assessment of Adult Literacy (NAAL)



Linking Health with Adult Basic Literacy Education (ABLE)

- ABLE
 - Highly skilled adult educators
 - Build the skill set needed to fulfill their roles as parents, workers, citizens, & patients
- Public Health
 - Working with vulnerable population
 - Difficulty delivering services

Take Charge of Your Health (TCYH); a participatory health literacy curriculum for adult learners

Collaboration with the Center for
Literacy (CFL; Philadelphia)

Women with Low literacy

- S-TOFHLA Inadequate or Marginal
- TABE Locator E and M

The Goal

- Integrate adult literacy instruction with relevant health information and health navigation skills
 - Provide skills that are transferable
 - Keep learners interested in the classes
- Participatory Curriculum to Increase relevance and interest in classes

Philadelphia Preterm Prevention Project

- Recruited immediately after an early preterm birth (<35 weeks gestation)
- 18 months of intervention

TCYH Intervention

- Classroom Model
 - Initial structure 7/04-5/05
- Individualized Home Visiting Model
 - Modified to address obstacles to participation (6/2005 – 8/2008)

TCYH- Classroom

- Full FTE adult educator
- 2, 1 and ½ hour instructional sessions per week
- English and ESOL able
- Food provided during the session
- Transportation help provided (tokens or parking)
- Computers and internet access

Outcomes of Classroom Model

- Low Participation
 - 11% of those eligible (n=38)
 - 21% of those who accepted (n=19)
 - 2 participants completed 20 hours instruction
- Particular interest in web focused instruction

Obstacles to TCYH

Competing priorities

1. Complex lives
2. Vulnerable population

Transportation and childcare

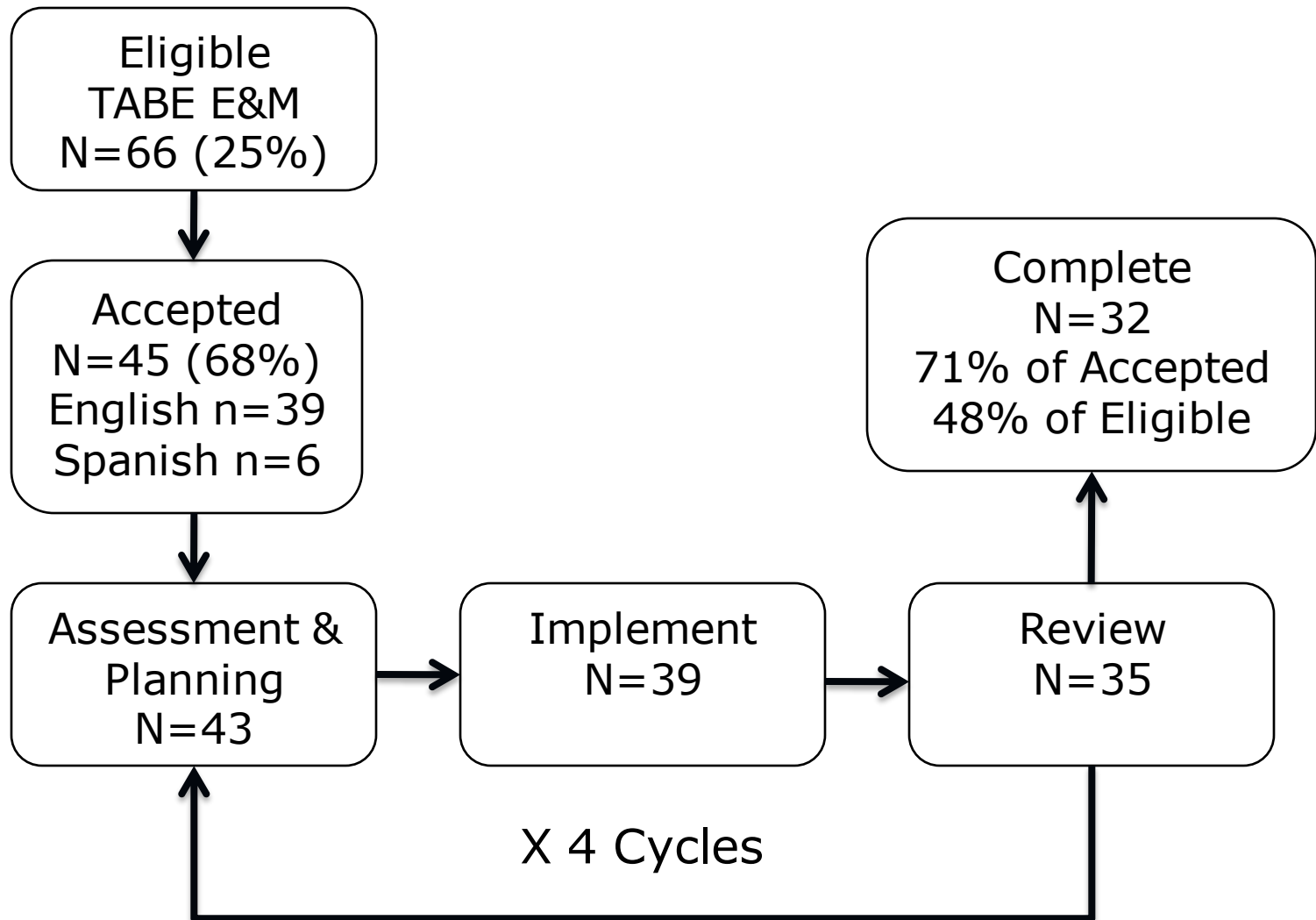
Scheduling inflexibility

1. Set times
2. Only two classes per week

TCYH Goal: Individualized Home Visitation Model

- Based on a home visiting model for women with young children
- Emphasis on health care navigation (Health Literacy)
- Learner directed topics
 - The priorities of the participant

TCYH-GOAL



Goal-Themes

- Medical Care
 - Primary care (child and mother)
 - Specialty Care
- Family Management & Economics
 - Insurance, employment, housing, child services
- Education
 - Secondary Education
 - Adult Education

Outcomes for TCYH-GOAL

- High Participation
 - 48% of those eligible (n=66)
 - 71% of those who accepted (n=45)
 - 62% of those who accepted completed program (20 hours instruction)
- Linking of disparate health navigation needs
- Educational outcomes of a health literacy program

Conclusions

- Linked health and literacy curricula can be successfully delivered
- New models are needed to work with women who are not looking for educational programs
- Future work is needed to evaluate the benefits of such public health and literacy collaborations

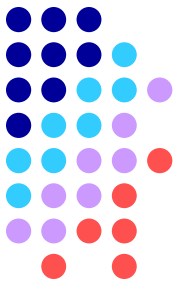
Multidisciplinary Health Literacy Project and Curriculum

Susan R. Levy, PhD, FASHA
University of Illinois at Chicago,
Institute for Health Research &
Policy

National Institute for Literacy
Webcast

Washington, D.C. Sept. 16, 2008

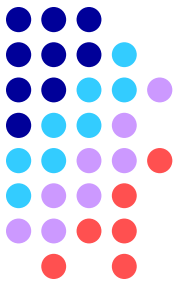




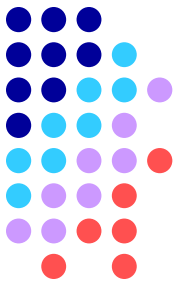
Project Summary

- **A randomized, controlled study to test the relative effectiveness of different curricula and different program structures on adult literacy.**
 - Target population: Adult education programs in Illinois.
 - Funded 2002-08 by the National Institute for Literacy (NIFL), the National Institute of Child Health and Human Development (NICHD), and the U.S. Department of Education (OVAE)
 - Grant # 1 RO1 HD4 3761

Project Summary (cont.)



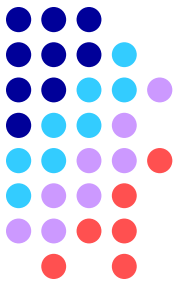
- Ultimate Goal: Health Literacy curriculum will develop general adult literacy skills as well as improve health-related knowledge, self-efficacy, and potentially, health promoting behaviors



Health Literacy

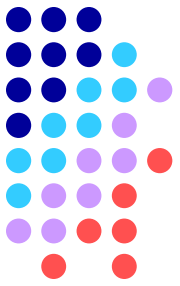
- Literacy is broadly defined as “an individual’s ability to read, write and speak, and compute and solve problems at levels of proficiency necessary to function...” (National Literacy Act, 1991)
- Health literacy is “the ability to read, understand, and act on health care information” (AMA, 2002).
- Imperative to integrate points of view addressing above definitions in project.

Health Literacy Affects Health



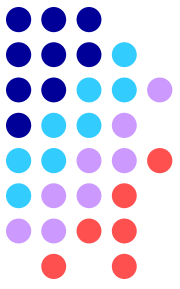
- Correlation between low literacy and poor health well documented –
 - 45% of adults cannot understand printed health information
 - 26% cannot understand when their next appointment is scheduled
 - 42% do not understand the instruction to “take on an empty stomach”

Health Literacy Affects Health



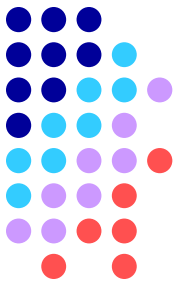
- Adults with low health/literacy
 - Experience annual healthcare costs four times higher than those with higher health literacy
 - Cost the health care system as much as \$73 billion per year (AMA Foundation, 2006)

Adult Health Literacy Curriculum



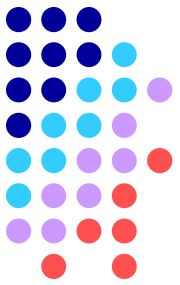
- 42 classroom hours
- Explicit instruction
- Theoretically driven
- Researchers hypothesize that health content and its relevance will personalize student interest in the adult literacy curriculum, leading to greater increase in literacy as well as greater health knowledge and ability

Adult Health Literacy Curriculum (cont.)

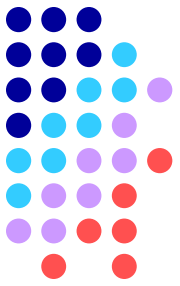


- Prioritized Content includes:
 - Introduction to health care
 - Health care institutions/professionals
 - Health history
 - Health terminology
 - Physical activity
 - Nutrition
 - Medications

Curriculum Content



- Curriculum health content and activities developed across adult education literacy levels
- Curriculum designed around concepts of adult education, and includes comprehensive reading and literacy skills, and practical simulated health situations and activities

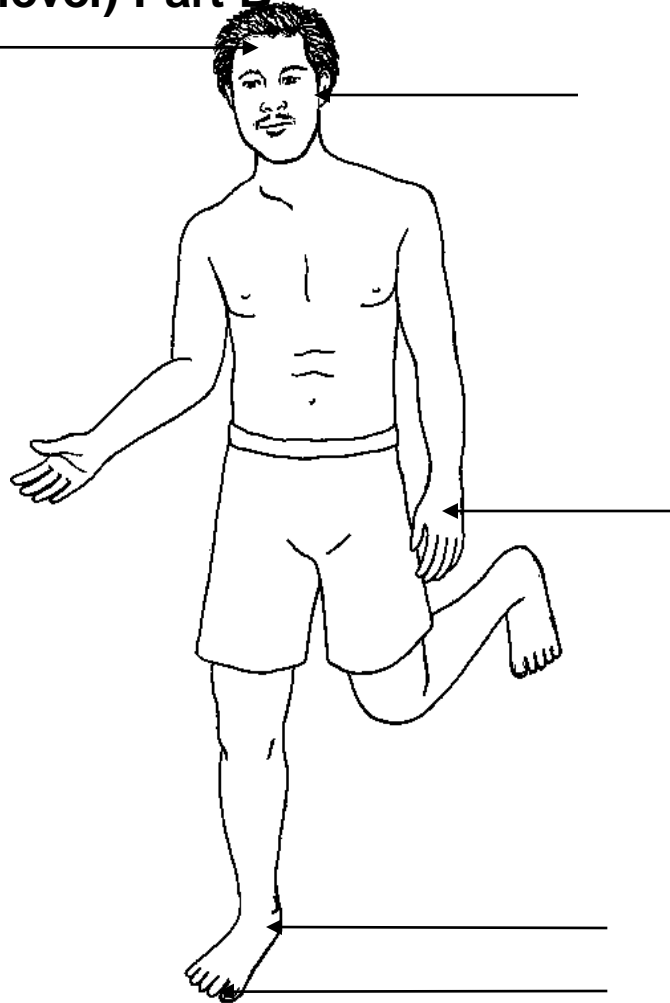
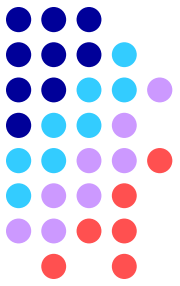


Literacy Skills Addressed

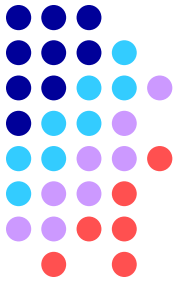
- Listening
 - e.g.: Formulating questions; Problem solving
- Speaking
 - e.g.: Dialogs; Role Plays
- Reading
 - e.g.: Informational reading; Authentic reading
- Writing
 - e.g.: Forms; Essays

Curriculum Examples

Parts of the Body, (Basic level) Part B



Curriculum Examples (cont.)



Vocabulary practice – Basic level

Directions: Circle the correct symptom/health problem for each picture.

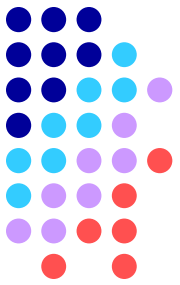


- a. cough
- b. fever
- c. chills



- a. runny nose
- b. dizzy
- c. diarrhea

Curriculum Examples (cont.)

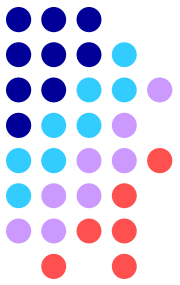


Word Forms, Part A: Section 17

Directions: Read each sentence out loud with your class. With a partner, make a check (✓) on the chart to show if the underlined word is a noun or a verb.

	Noun	Verb
1a. Doctors <u>examine</u> you to see if you have a health problem.	_____	_____
1b. Before your <u>examination</u> , you have to fill out some health forms.	_____	_____
2a. The doctor <u>prescribed</u> a medication for Peggy.	_____	_____
2b. Peggy took the <u>prescription</u> to the pharmacy.	_____	_____

Curriculum Examples (cont.)

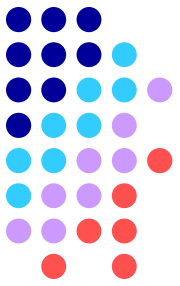


Patient Information Form

Directions: You are the patient. At home, fill out this form with your information.

1. Last name: _____
First name: _____ Middle initial: _____
2. Street address: _____
City: _____ State: _____
Zip code: _____
3. Date of birth: _____
(month, day, year)
4. Social Security Number: _____
5. Marital status -- put a check mark (✓) on the correct blank:
Single _____ Married _____ Divorced _____ Widowed _____
6. Occupation/job: _____
7. Employer's name: _____
8. Employer's street address: _____
City: _____ State: _____
Zip code: _____

Curriculum Examples (cont.) – (All levels but beginning)

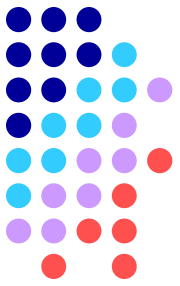


Personal Medication Lists as of _____ (date)

Over-The-Counter Medications: Use the chart below to record all of the over-the-counter medications you are taking. Be sure to update the list when you start taking a new medicine (including vitamins and herbal products).

Name	Why do you take it? (allergies, headache, upset stomach, etc.)	Dosage (medication strength or amount)	How do you take it?	Doctor's Name (if recommended by a doctor)
<i>Example: Extra Strength Tylenol</i>	<i>Arthritis pain</i>	<i>1,000 mg (2 caplets) every 6 hours</i>	<i>4 or 5 times a month</i>	<i>None</i>

Curriculum Examples – Role Play



2.a. You are a doctor.

Ask the patient the following questions:

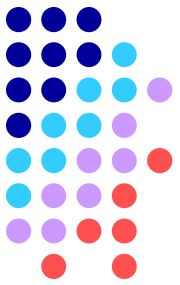
1. Why are you here today?
2. Has your appetite changed?
3. When did this start?
4. Do you have any pain or feel ill when you eat?
After you eat?
5. Where is the pain?
6. Have you tried eating different kinds of foods?
7. Have you taken any new medication before this started?
8. How are things going in your life right now?
Have you been worried or upset about something?

2.b. You are a patient.

You have come to the clinic because you have had trouble eating for the past two weeks.

Answer the doctor's questions about your appetite problem.

Curriculum Examples (cont.)

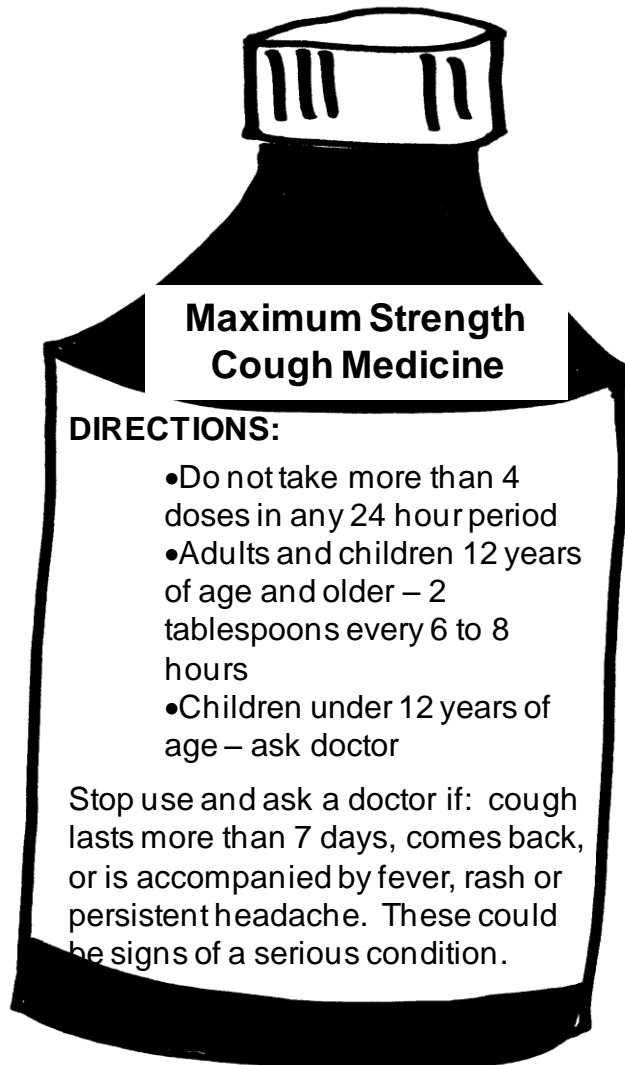
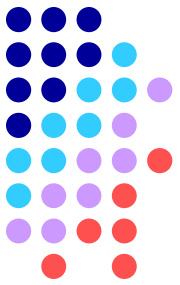


Expiration Dates

Directions: Look at today's date. Look at the expiration date. Put a check (✓) on the chart to keep the medication or throw it away.

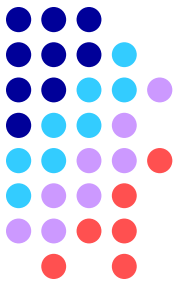
	Today's Date	Expiration Date	Keep the Medication	Throw Away the Medication
1.	June 6, 2003	May 2003		✓
2.	February 26, 2004	Sept. 2006		
3.	04-13-04	2003/05		
4.	12-02-03	11/2003		
5.	April 10, 2004	05-2004		

Curriculum Examples (cont.)

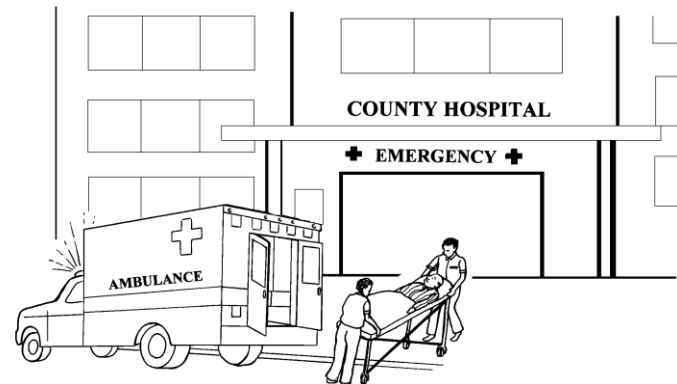
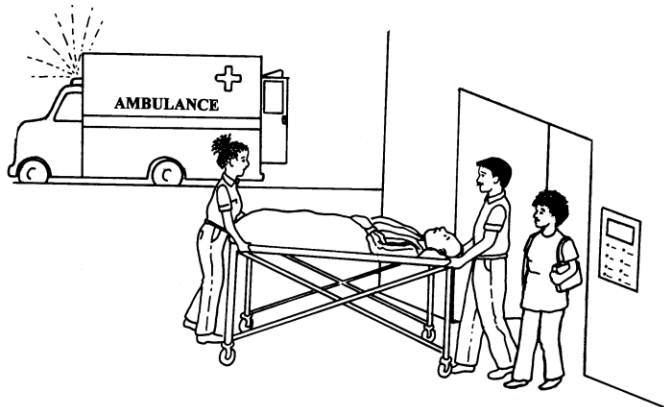
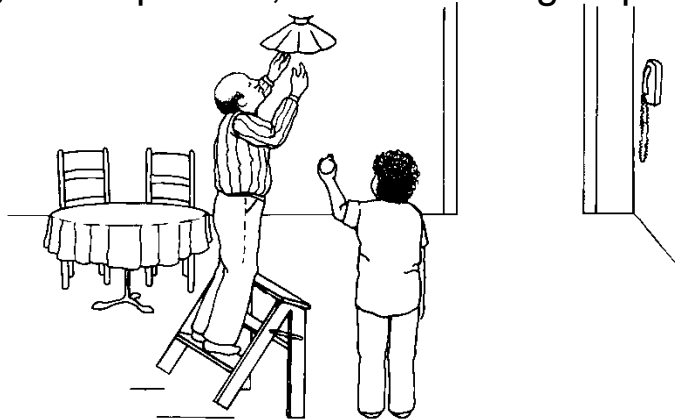


	True	False
1. The dosage is 2 teaspoons every 4 hours.		
2. You can take 4 doses a day.		
3. The dosage for children under 12 is the same as for adults.		
4. Adults should take 2 tablespoons every 6 to 8 hours.		
5. You can't take this medication any longer than 8 days.		
6. A fever, rash or persistent headache could be a sign of a serious condition.		
7. If the cough comes back, you begin taking the medication again.		

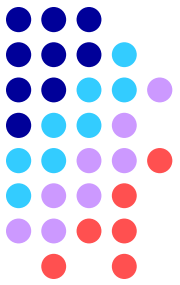
Curriculum Examples (cont.)



Directions: Look at the pictures below and write a story about this emergency or you may write a story about your own experience. Your teacher will tell you if you should write the story by yourself, with a partner, or in a small group.



Curriculum Examples (cont.)



An Emergency or Not?

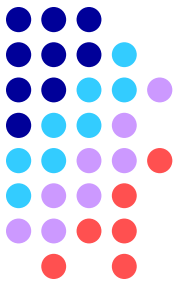
Directions: With a partner, choose at least three situations below and decide what action to take, if any. If you think it's an emergency, then an action would be to call for an ambulance (call 911) or take someone to the hospital emergency room or an immediate care center. If it's not an emergency, then an action might be self-care or calling the doctor's office. Be prepared to explain your actions.

Situation#7

Jean, 25 years old, tripped and fell on the sidewalk outside where she works. She got up unhurt, and then realized that one of her front teeth had been knocked out. She found her tooth lying on the sidewalk and ran back into her office. She was bleeding, so she began rinsing her mouth with cold water. To make the bleeding stop, she pressed an ice cube wrapped in a towel where the tooth had been.

What should Jean do? Is this an emergency? What would you do?

Curriculum Examples (cont.)

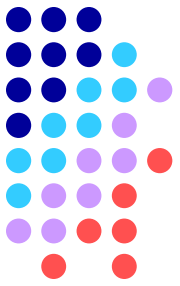


Getting Healthier Action Plan Example

Directions: Mike wants to be healthier and make good health decisions. He wants to make a few changes in his life. Look at his plan, then fill in your own plan. Start with just a few changes. When you finish, talk about your action plan with a partner.

	Healthy Things I Do	Unhealthy Things I Do	Changes I Want to Make	What I Need to Do
physical activity	walk 15-30 minutes a day	watch TV 2-3 hours a day	exercise 30 minutes a day, and watch less TV	make a schedule substitute TV with exercise
nutrition	eat balanced meals			
preventive care		my last checkup was 5 years ago	get a checkup	call the doctor

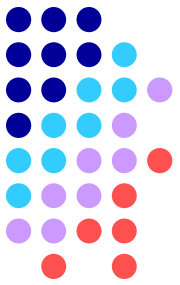
Curriculum Examples (cont.)



Self-Help Analysis

Directions: Using the information from your Personal Physical Activity Log, the Reading Passage sections on physical activity, and the article, “Physical Activity and Health,” describe your overall habits for doing physical activity. What days of the week or time of day do you do more physical activity? Are your physical activities less vigorous or more vigorous? Can you make them more vigorous? Are you satisfied with the physical activities you are doing? Are there any physical activity changes you would like to make?

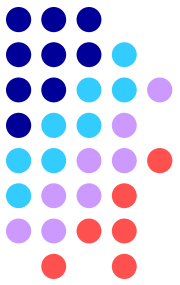
Participants



	Wave 1	Wave 2	Wave 3	Wave 4	Wave 5	Total
# of Sites	11	11	10	7	3	42
# of Classes	26	34	33	18	9	120
# of Adults*	362	588	654	272	70	1946

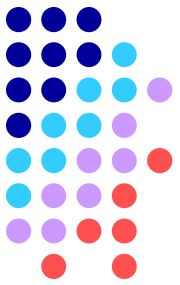
*Participants with Pretest TABE, BEST, CELSA, or Health Literacy Assessment

Data: Waves 1-5



Group	Frequency	Percent
Experimental	971	49.9
Control	975	50.1
Total	1946	100.0

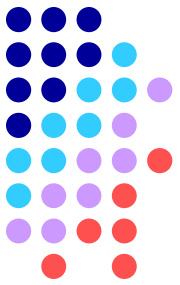
Data: Waves 1-5



	ABE/ASE		ESOL	
Level of Instruction	N	%*	N	%*
Literacy/Beginning	71	3.7	624	32.8
Intermediate	348	18.3	522	27.5
Advanced	89	4.7	159	8.4
ASE	88	4.6	--	--
Total	596	31.4	1305	68.6

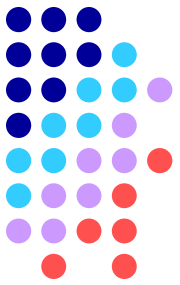
*Percent of total sample.

Data: Waves 1-5: Demographics



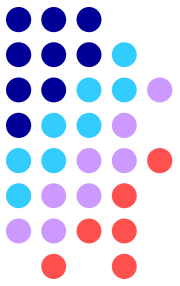
Characteristic	N	%
Gender		
Male	469	24.5
Female	1449	75.5
Hispanic/Non-Hispanic		
Hispanic	1027	53.6
Non-Hispanic	888	46.4

Data: Waves 1-5: Demographics



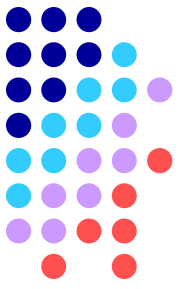
Characteristic	N	%
Primary Home Language		
English	565	29.4
Spanish	1107	57.6
Other	249	13.0

Data: Waves 1-5: Mean Pre-Test Health Knowledge Scores



Pre-test Literacy Level	N	Mean
ABE		
Literacy/Beginning	63	10.82
Intermediate	284	14.04
Advanced	75	16.76
ASE	80	18.56
ESOL		
Literacy/Beginning	494	9.42
Intermediate	431	11.17
Advanced	141	13.60
TOTAL	1613	11.94

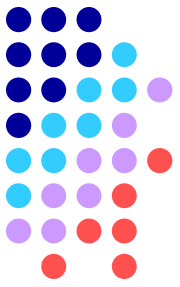
Waves 1-5: Effects on Health Knowledge



- **The average post-test health knowledge score is significantly higher than the average pre-test health knowledge score**
 - **The pre/post gain is significantly greater for the experimental group whether ESOL or ABE/ASE**
 - **Adults increase their health knowledge when participating in classrooms using the health literacy curricula**
 - **Adults increase their health intentions and efficacy using the health literacy curricula**

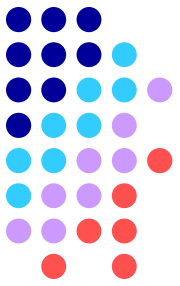
Preliminary Data: Waves 1-5

Pre/Post Literacy Mean Score Comparisons



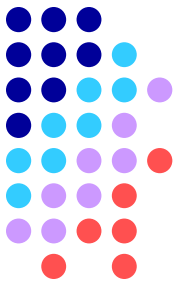
Test	Pre-test	Post-test	N	P value
TABE	529.56	538.78	283	$p \leq .0030$
BEST	42.89	49.17	633	$p < .0001$
CELSA	40.85	43.34	144	$p \leq .0001$

Waves 1-5: Effects on Literacy



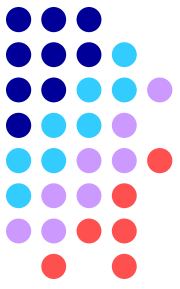
- **Adults in experimental and control groups make gains in literacy**
 - **In our study, control teachers received training in literacy strategies and embedding strategies**

Implications

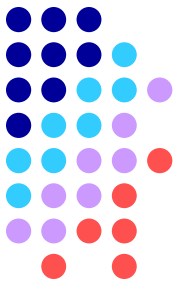


- Data show direct and progressive association between literacy level and health knowledge, intentions, and self-efficacy (low to high)
- Study has begun to differentiate needs/uses of health information by low literate adults

Implications (cont.)

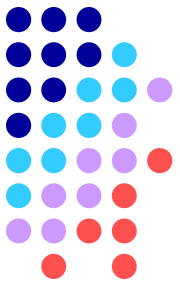


- Data indicate control students show greater health-related deficits at post-test than experimental students at same literacy levels; ESOL male controls remain highest risk.
- Our belief is that lower literacy levels need more than 42 instructional hours to progress to next literacy level; while health knowledge and related efficacy can be significantly improved relatively quickly, even within the “up to” 42 hours



Policy Implications

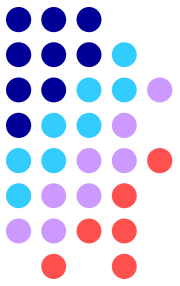
- Curricula need to differentiate between ABE/ASE and ESOL concerns and interests, especially at lower levels
- Greater focus on males in general and especially ESOL males in recruitment and retention may benefit adult literacy programs greatly and male health literacy in particular



Policy Implications (cont.)

- Literacy levels and health literacy levels are proven to be correlated from low to high; thus providing further evidence that adult literacy education needs to be a national priority
- The most vulnerable adults in respect to overall health and mortality will continue to be highly populated by those adults with the lowest literacy skills. The cost of health care will continue to escalate if literacy is not addressed.

Practical Lessons Learned



- Integrate 42 hour Health Literacy Curriculum with other adult literacy materials over the course of a semester to keep students involved
- Research format too focused for higher literacy level if not integrated